

Zoom: https://dhswi.zoomgov.com/j/1603654162?pwd=VzBzNEZicFZLbm9nN051QWhlcGl5QT09

Meeting ID: 160 365 4162

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Minutes

Meeting Members:

Χ	Dr. Nick Antos		Emily Kittell	Χ	Leah Ricci
	Jonette Arms	Χ	Laura Leitch	Χ	Dr. James Schauer
Χ	Dr. Mei Baker	Χ	Sharon Luu	Χ	Dr. Bob Steiner (Chair)
Χ	Dr. Donald Basel	Χ	Dr. Katie Marquart	Χ	Dr. Julie Thiel
	Anna Benton	Χ	Dr. Anne Marsh		Angie Thompson
Χ	Dr. Jeff Britton	Χ	Dr. Roberto Mendez		Tamara Thompson
	Leah Eckstein	Χ	Emily Meyer		Paula Tran
Χ	Dr. Norm Fost	Χ	Dr. Michelle Miller		Jennifer Ullsvik
Χ	Dr. John Hokanson		Dr. Pilar Ossorio	Χ	Isabella Walters
Χ	Tami Horzewski		Susan Picione	Χ	Mary Marcus Walters
Χ	Dr. Julie Kessel	Χ	Mandy Quainoo		Dr. Jasmine Zapata
Χ	Alison LaPean-Kirschner				
M	eeting Guests:				
Χ	Emilie Blair	Χ	Zoe Culshaw-Klein		Taylor Duke
Χ	Sharon Gilbert		Dr. Elizabeth Goetz	Χ	Dr. Scott-Schwoerer
Χ	Emma Wagner	X	Kimberly Haugstad	X	Susheela Jayaraman
Χ	Dean Suhr	X	Wanda Meteer	X	Sara Zoran
Х	Bryan Polcyn				

Agenda:

	Friday, December 6, 2024 10:00 a.m. – 2:00 p.m.					
Time:	Time: Topic: Lead: Follow-up Items: Notes:					



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10:00 - 10:10	Welcome Review and Approval of Past Meeting Minutes	Dr. Steiner	Motion to approve May 3, 2024 minutes. 1st motion: Dr. Jeff Britton 2nd motion: Dr. Jamie Schauer Motion approved.
			Dr. Thiel and Tami Horzewski shared the following DHS updates: • Dr. Steiner is back with the NBS Program part-time in the role of DHS NBS Program Medical Director. He works primarily on Tuesdays and Thursdays and every other Friday.
10:10 - 10:20 10:20 - 10:35	Department of Health Services (DHS) Updates WI State Lab of Hygiene (WSLH) Updates	Dr. Thiel/Tami Horzewski Dr. Baker	 The NBS Program is part of the Family Health Section (FHS). The new FHS Manager, Leah Eckstein, recently started and may join some future meetings.
			 The Title V, five year needs assessment for setting priorities for maternal and child health work is underway. There were focus groups and a state-wide survey. This information is being analyzed and we are looking at setting



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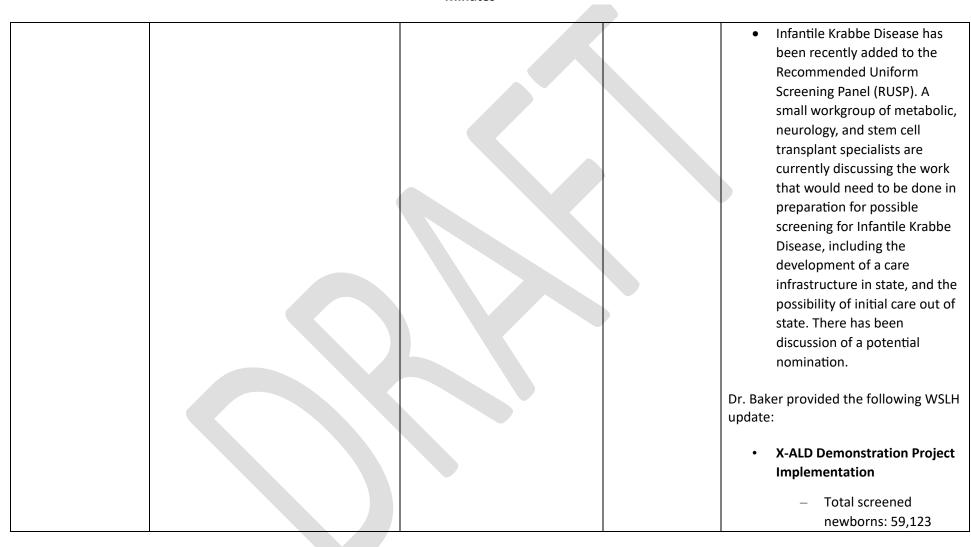
	priorities for the next 5 years,
	2026-2030.
	 As mentioned at the previous meeting, DHS will be relocating to a new office/building. The move is now scheduled for next fall, 2025.
	 Rulemaking for the NBS blood card fee increase and the addition of two conditions to the NBS panel, X-ALD and MPS 1, is moving through the process. The legislative report is in the Governor's Office for review and addressed the comments received during the public hearing/comment period. Rulemaking review will resume when the legislative session begins around January
	2025.



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		(9/20/2023 – 9/19/2024)
		 Reported screen positive: 6 male and 8 female
		Confirmed: 5 male (including 1 ZWS) and 5 female
		 Other outcomes: 2 false positive (1 male and 1 female)
		 1 further clinical follow up declined (
		known carrier mother)
		- 1 pending (female)
		- Opt- Out: 20
		 HRSA-23-065: State Newborn Screening Priorities Program (NBS Propel)



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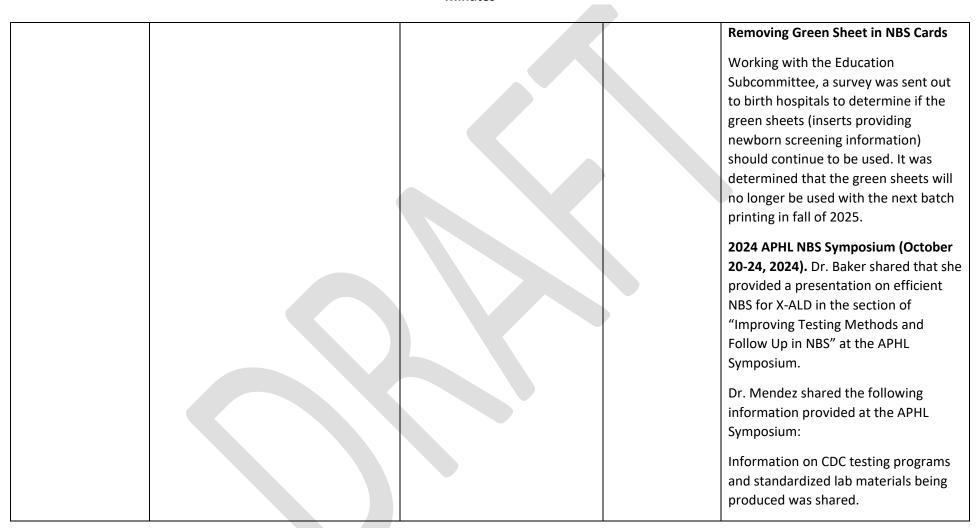




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			There were discussions on the feasibility of Whole Genome Sequencing (WGS) and NBS – equity for follow up, and storage and protection of data and how AI could be used. There were also discussions on education for families, the importance of inclusion, short term and long term follow up, and information on Lysosomal Storage Diseases, to name a few highlights.
10:35 – 10:45	National Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)/Recommended Uniform Screening Panel (RUSP) Update	Dr. Steiner	Dr. Steiner shared the following ACHDNC update: Public comment was heard that consisted primarily of advocacy for NBS for Biliary Atresia, Cerebrotendinous Xaanthomatosis (CTX), and Duchenne Muscular Dystrophy (DMD). DMD: nominators have apparently requested a pause in the process, The Metachromatic Leukodystrophy (MLD) nomination was approved for Evidence Review, a brief report was



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			R	iven on the progress of the Evidence leview. Infantile Krabbe and Guanidinoacetate
			M a R	Methyltransferase (GAMT) Deficiency re the most recent additions to the ecommended Uniform Screening
			T L:	here was an update on the aboratory Developed Tests (LDT) —an DA initiative to regulate them. The
			LI re d	DT issue and presentations on esearch funding opportunities to ocument lived experience of patients and Families was shared.
			V	Vor. Fost shared the following Research Vorkgroup update: The Research Workgroup has been
	NBS Research Workgroup Update		m d	neeting monthly. The group has been iscussing the development of policy guidelines for research using NBS
10:45 – 11:00		Isabella Walters/Dr. Fost	h -\	ried blood spots (DBS). The discussion as included the following questions: who should be involved?
			-(does it need to be an investigator? does it need to be someone in WI? what credentials do are needed? who should be reviewing?



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			-should the review go through the committee process and/or a review group at DHS? -how to address issues with consent and opt-in or opt-out mechanisms? -what to do with incidental findings? -how to address issues with IRB review and the steps/process for IRB review? -are there certain qualifications needed for IRB review? The workgroup should be wrapping up and providing their proposed draft guidelines by February. A draft will be sent to the Umbrella Committee and SACNBS for review. It will then be sent to the DHS Secretary for review.
			Currently there is no research proposal process in place.
11:00 – 11:25	Guanidinoacetate Methyltransferase (GAMT) Deficiency Nomination/Background	Drs. Mendez/Scott-Schwoerer	Dr. Scott-Schwoerer shared background information on GAMT addressing the required review criteria. She provided information on diagnostics, symptoms, natural history, current and recommended treatment, follow-up, management, and outcomes. GAMT is on the



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			recommended uniformation. Assay of progress.	endez provided nd follow up
			The 14 Umbrella Comembers reviewed nine nomination rev	and voted on the
11:25 – 11:50	GAMT Criteria Review & Voting	Dr. Steiner/Tami Horzewski	Criteria 1 - Mandate limited to conditions serious health risks are unlikely to be de prevented in the absorber screening. Vote: 14 - meets	s that cause in childhood that etected and
			Criteria 2 - For each should be information incidence, morbidity and the natural histo Vote: 14 - meets	on about the and mortality,
			Criteria 3 - Condition newborn screening s with interventions the shown in well-design	should be linked hat have been



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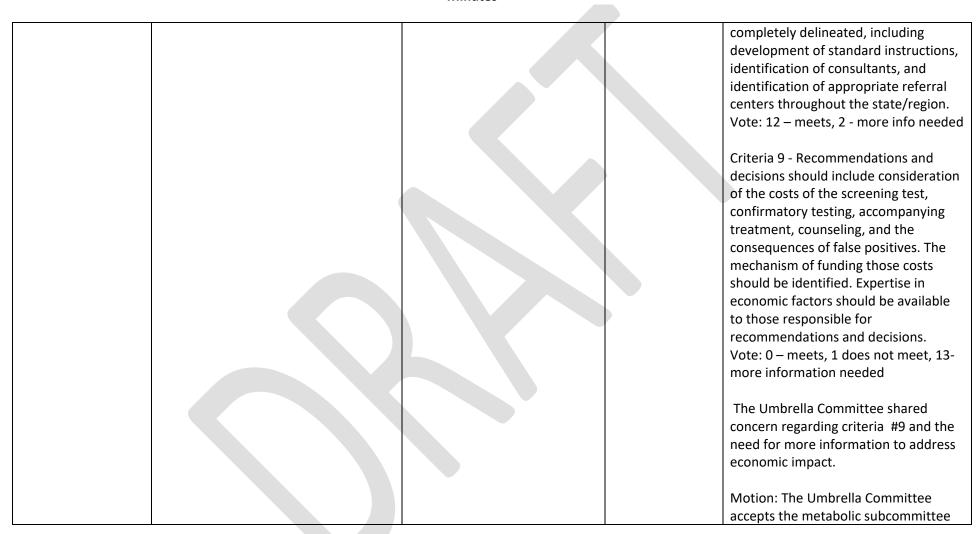
	safe and effective in preventing serious
	health consequences.
	Vote: 14 - meets
	Criteria 4 - The interventions should be
	reasonably available to affected
	newborns.
	Vote: 14 - meets
	Criteria F. Annuarriata fello
	Criteria 5 - Appropriate follow-up
	should be available for newborns who
	have a false positive newborn screen. Vote: 11 - meets, 3 more information
	needed
	needed
	Criteria 6 - The characteristics of
	mandated tests in the newborn
	population should be known, including
	specificity, sensitivity, and predictive
	value or other convincing.
	Vote: 14 - meets
	Criteria 7 –
	N/A
	Criteria 8 - Before a test is added to
	the panel, the details of reporting,
	follow-up, and management must be



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			recommendation to add GAMT to the WI NBS panel pending additional information regarding economic impact. • First Motion: Dr. Basel • Second Motion: Dr. Britton Motion approved (10 – yes, 3-abstain, 1-no). There was an additional Motion to table: • First Motion: Dr. Schauer • Second Motion: Dr. Antos
			Motion not approved (3-yes, 10-no, 1-abstain).
11:50 – 12:00	Break		
			Dr. Steiner provided some background
			information on ASMD addressing the
	Acid Sphingomyelinase Deficiency		required review criteria.
12:00 – 12:10	(ASMD)/Niemann-Pick Disease	Dr. Steiner	It was noted as the co-nominator that
	Nomination/Background		conflict of interest was disclosed, and
			the intention was to provide clinical
			expertise and information for the



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			nomination, rather than advocacy for the condition nomination.
12:10 – 12:30	Acid Sphingomyelinase Deficiency (ASMD)/Niemann-Pick Disease Criteria Review & Voting	Dr. Steiner/Tami Horzewski	The 14 voting Umbrella Committee members reviewed the metabolic subcommittee recommendations and nine criteria for the review of the ASMD nomination. Motion: the Umbrella Committee recommendation follows the recommendation of the Metabolic Subcommittee that ASMD should not be added to the WI NBS panel at this time because additional information is needed. 1st motion: Dr. Britton 2nd motion: Dr. Hokanson Motion approved. (13-yes, 1-abstain) The Umbrella Committee recommendation will be forwarded on to the Secretary Advisory Committee on Newborn Screening (SACNBS) for the nomination review at the March 14, 2025 meeting.



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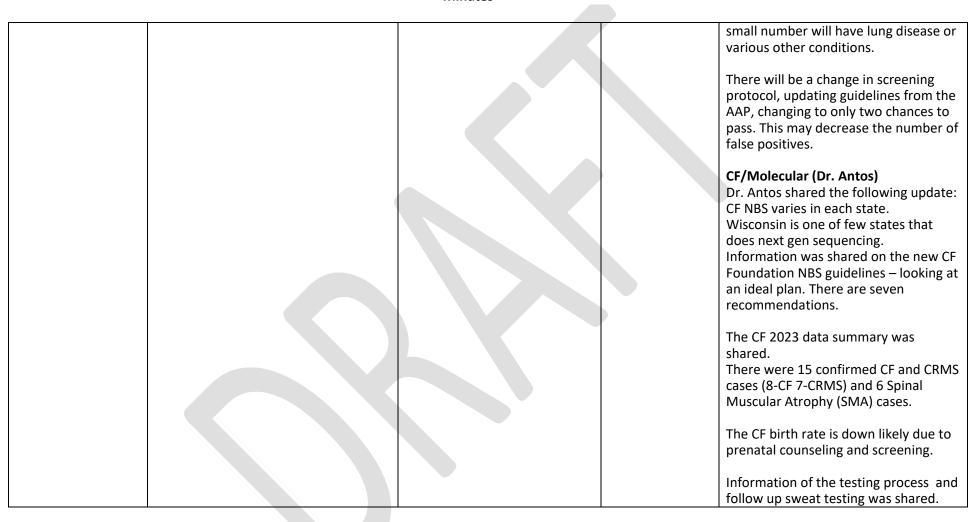
12:30 – 1:45	Subcommittee Updates Secretary's Advisory Committee on Newborn Screening (SACNBS) Update	All Chairs (CCHD, CF, Education, Endocrine, Hearing, Hemoglobinopathy, Immunodeficiency, and Metabolic) Dr. Fost	CCHD (Dr. Hokanson) Dr. Hokanson shared the following update: About 1/1,000 babies fail their screening for various reasons. By updating the blood card more data will be in WE-TRAC so that every baby that needs to be screened is screened. Query has been done looking at just reporting on those babies that need to be screened and not those that already have a known heart condition. During the period of 2014-2022, there were 571, 000 babies in this cohort, 1,000 have a congenital heart diagnosis prenatally and for those diagnosed in a timely fashion before leaving the hospital or 3 days after a homebirth, 42 babies were diagnosed through pulse oximetry. That is approximately 5 babies/year, per the 42 in 9 years. About 102 had late diagnosis with various conditions. The rate of prenatal detection will plateau. The late diagnosis going down, and those identified in a timely fashion postnatally decreased also. Outcomes of babies that failed their echo show 34 had a significant heart disease but didn't classify with the targeted conditions of the screening. A
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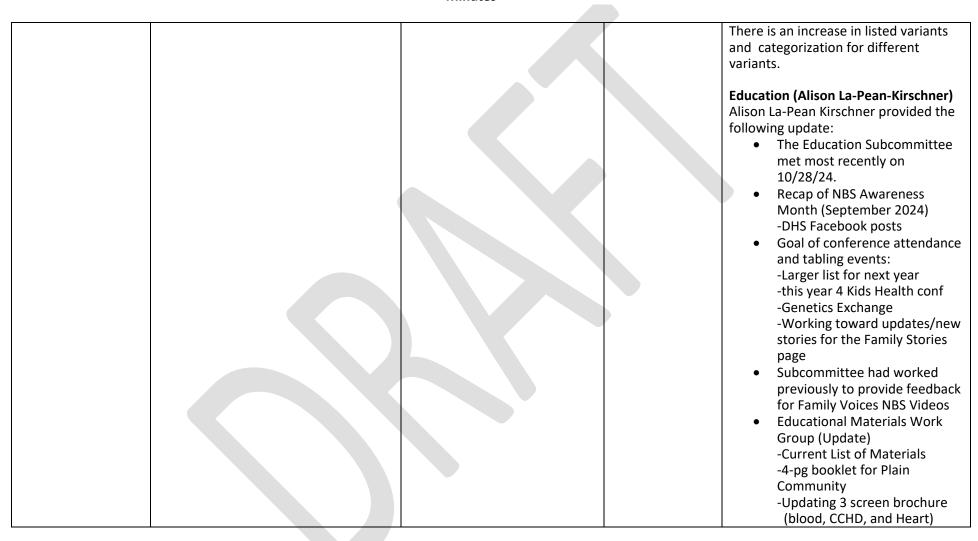




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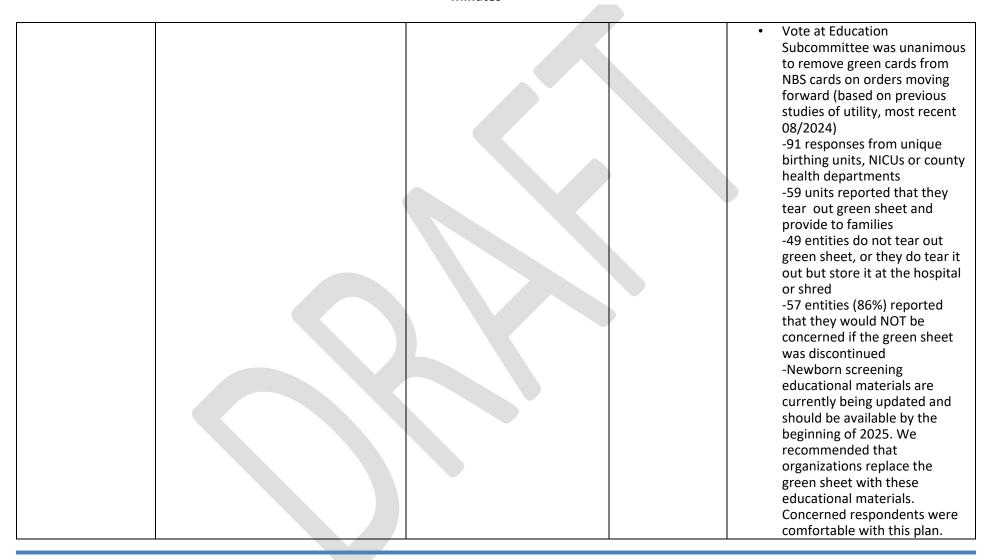
	-Hearing follow-through postcard -Updating poster and sticker -Working with UW Media solutions for graphics -Updated drafts are expected back 12/18 with an internal working group meeting on 1/2/25 to reviewRedcap survey to elicit feedback when materials are ready for review outside of our subcommitteePlanning for final versions and printing early in 2025. Discussed Continued Efforts (and renewed effort moving forward) to engage with NBS education in the prenatal sphere -Specific focus on Community -Partnerships -Engagement with 2-3 organizations, in-person event opportunities -Possibility of creating a "train the trainer" info package or session for those engaging in
	the trainer" info package or



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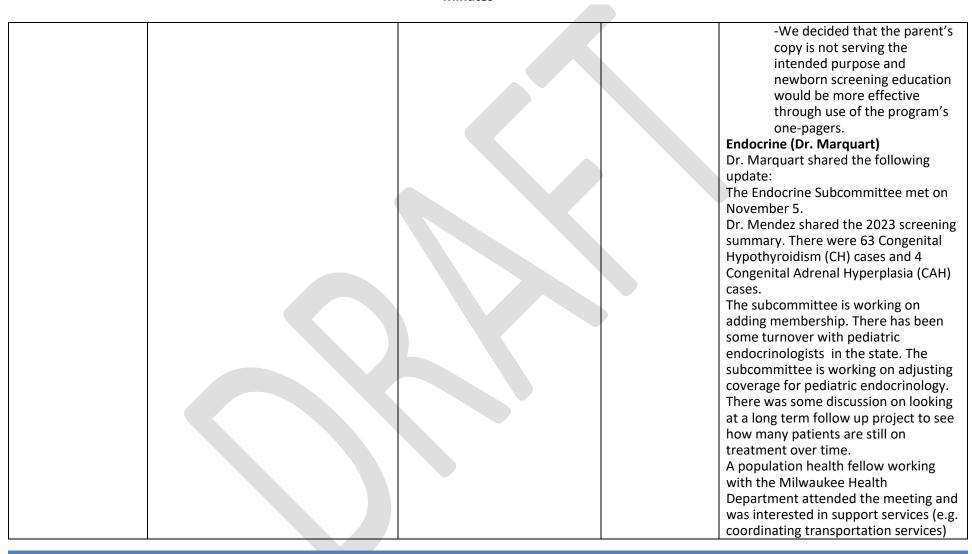




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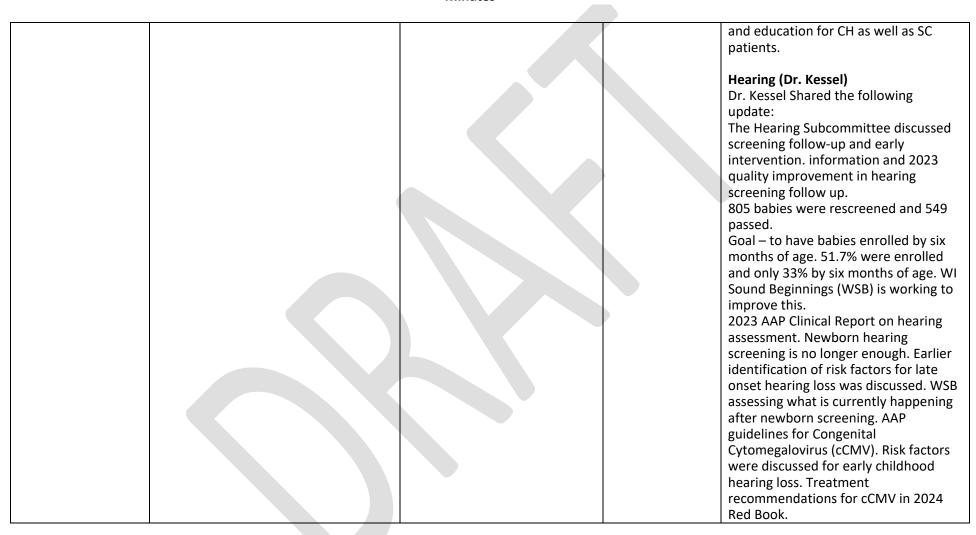




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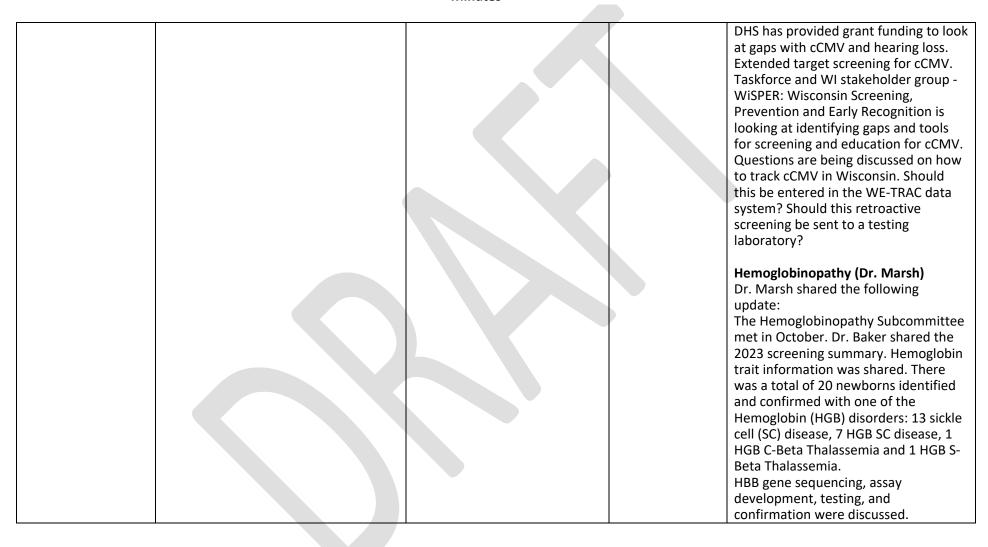




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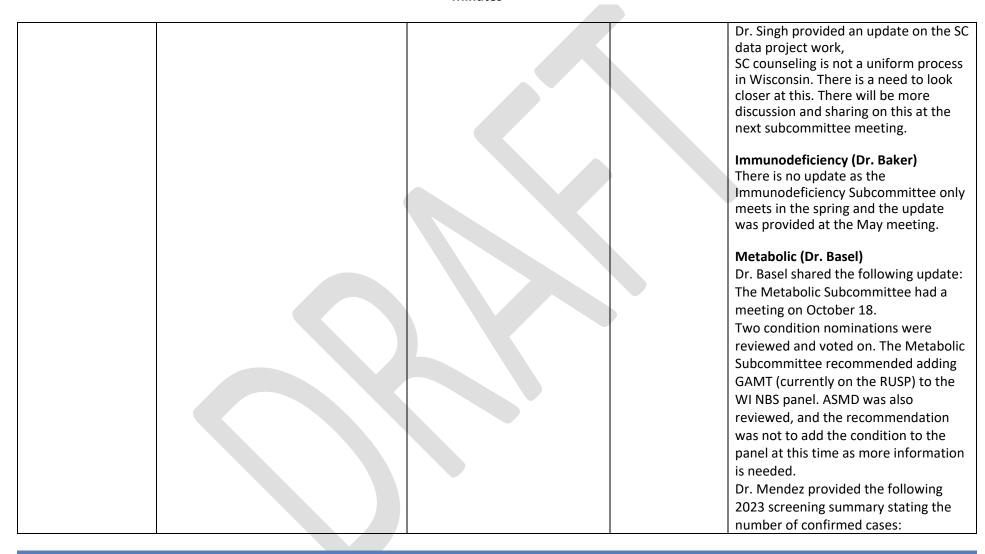




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			•3 confirmed cases of Galactosemia •6 confirmed cases of late onset Pompe Disease •6 confirmed cases of PKU •8 confirmed Organic Acidurias •2 confirmed Fatty Acid Oxidation Disorders Dr. Baker provided an update on the X- ALD NBS Demonstration project. Six males and eight females were reported as screen positives. A workgroup is looking at Krabbe Disease and how to mobilize rapid transplant that will be required for treatment. The subcommittee will be reviewing
1:45	Plan Next Meeting/Agenda Items	All	MPS 2 at a future meeting. The next meeting will be on Friday, May 2, 2025. • 2024 Screening Summary • Suggested review of false positive data and what is published on adverse effects of false positives in NBS • X-ALD follow up with grant ending • Revisit the role of the Umbrella Committee



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Minutes

Next meeting date: Friday, May 2, 2025

"Parking Lot" Items: